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Involving Fathers in Ante-natal Screening for Sickle Cell Disorders: Improving Informed Decision Making

SUMMARY OF RESEARCH PROJECT FINDINGS

Introduction

Facilitating informed choice among those at risk of recessive disorders is a key NHS policy objective. In 2001, the Department of Health established the Sickle Cell and Thalassaemia Screening Programme (now part of Public Health England). One of the aims of the programme is to provide timely ante-natal sickle cell screening to all couples, who might be carriers of sickle cell.

Sickle cell disorders are inherited blood disorders which can have an impact on a person's quality of life (for more information see www.nhs.uk/conditions/sickle-cell-anaemia/Pages/Introduction.aspx). Both parents have to carry a genetic trait (sickle cell trait) before it can be passed on to their offspring. If they do, there is a one-in-four chance in every pregnancy that their child will be born with the disorder. Carriers can be identified by a simple blood test.

Ante-natal care is the care a woman receives when she is pregnant. During this care choices are offered about tests or screening for the woman and her baby. Ante-natal care involves fathers too. If a mother is identified as a carrier for sickle cell, ideally the father of the baby should be offered screening. This enables the couple to make an informed choice on the future of the pregnancy. Fathers, however, are not always tested, even when their partner is a known carrier. Little is known about why this is. Not engaging with fathers during ante-natal screening for sickle cell disorders creates local difficulties and threatens a national policy objective.

The Research Project

This qualitative research project was funded by the National Institute for Health Research (Research for Patient Benefit: Yorkshire and Humber). In partnership with voluntary sector organisations, it took place across England in Birmingham, Manchester, Leeds, Leicester, Liverpool, London, Sandwell and Dudley, and Sheffield.

The study included six focus group discussions with 50 young people. These were young people who were in relationships, aged 18–35, and from ethnic minority groups at possible risk of sickle cell disorders. We explored the extent to which men and women thought fathers should be involved in ante-natal care. We held discussions with men and women of African, African-Caribbean and mixed ethnic origins. We also conducted 24 in-depth semi-structured interviews with fathers to explore their experiences of ante-natal screening. In order to locate our findings within the ‘realities’ of service delivery we undertook 19 telephone interviews with professionals and two health commissioners involved in ante-natal screening.

We discussed our findings by holding advisory groups with stakeholders such as patients, families and interested members of the public who were primarily from ethnic minority communities. We held four advisory groups in London and two in Leeds. We also held three steering group meetings made up of academic, practice, policy, patient and family stakeholders. As the research project progressed we presented findings in community and practice settings.

Key Findings

There are many reasons why fathers find it difficult to be involved in ante-natal screening for sickle cell disorders. Some are the consequence of disadvantage and inequalities, others are associated with how services are organised. Men’s perceptions about the relevance of screening are equally important, along with their relationship with their partners and families. Examples of good practice also exist and we can learn from these. Our findings and recommendations for policy and practice are summarised here.

Ante-natal care as necessary routine

Ante-natal care is increasingly viewed by fathers and young people as a necessary routine, primarily aimed at women. Fathers did not have a problem with this; although they felt ante-natal care could make more of an effort to engage with them.

Most men and women did not realise they could be invited to have a test for sickle cell or if they had been tested, what the disorder was.

“...because even though I got tested (...) I didn’t know, even though I was told to get the test done, I didn’t still know much about sickle cell.”

FATHER, 32, AFRICAN ORIGIN

Some fathers also had no idea of the difference between sickle cell disorder and carrier status. Discussions with young people confirmed this, demonstrating a need for general awareness-raising, which they said should ideally begin before ante-natal care is offered.

“If they don’t [know] about the disease (...) they’re not going to know about the trait.”

YOUNG WOMAN, AFRICAN CARIBBEAN ORIGIN

Young people and fathers also spoke of the difficulty of making decisions, when they knew little about sickle cell and its consequences.

“In my circle of friends or family (...) it’s not something that we’re aware of, or it’s not something that’s talked about and it’s not the norm for you to just get tested and talk to other individuals and tell them.”

YOUNG WOMAN, AFRICAN ORIGIN

The words ‘disorder’ and ‘disease’ linked to sickle cell are understood negatively by fathers. Furthermore, some fathers who regarded themselves as asymptomatic did not see the need to be screened as they assumed they could not be a trait carrier. The perception of sickle cell as a ‘black’ or ‘ethnic’ disease persists among young people, fathers and practitioners too. This can sometimes cause confusion about why an invitation is given and to whom. It also means that screening can be perceived as stigmatising.

Young people and fathers associated screening with having a responsibility for the health of the child and to prevent disabilities. A minority of participants felt testing should be mandatory.

"I would recommend the test to other dads because it's got, it's just gotta be done and it's for the wellbeing of the child."

FATHER, 20, AFRICAN-CARIBBEAN ORIGIN

Knowing one's carrier status could also be useful in deciding who to have children with, which is why some fathers had been tested before entering ante-natal care or would have liked to have been tested before pregnancy. Fathers also spoke about finding out that they were carriers after their children were born but not being offered access to counselling.

Fathers of African origin or asylum seekers especially viewed screening as part of their citizenship duty. Young men, recent migrants and asylum seekers, however, were not always aware that they had a right to a GP, translation services or access to ante-natal care. Moreover, even the most educated and articulate fathers said there were times when they were overwhelmed by the complexity of information they received. They, therefore, struggled to understand what was going on.

"People struggle with the language, people struggle with the 'white coat doctor' or the very 'white, grey-headed specialists' that you're dealing with (...) I find it sometimes very intense and challenging (...) I am not saying challenged but economically challenged, so they're probably working nine to nine, doing twelve hours and stuff like, and all that processing all of this, you know, might also be a challenge."

FATHER, 38, AFRICAN ORIGIN

When services sensitively engaged with father's concerns, screening was seen as empowering. This, however, was rare, and most men felt that services were concerned with greater biomedical surveillance, thereby creating a further potential for stigma. Men believed ante-natal services treated them as an instrumental genetic 'risk' rather than expectant fathers, who had an interest in their partners and child's well-being. Some fathers also commented that they felt there was an element of blame and shame in being identified as a carrier,

which they associated with their ability to pass the condition on to their offspring. Young men and women agreed and said they struggled to initiate conversations about their carrier status with family and peers.

"I think a lot of is pride (...) because if you are told that (...) you've got this disease that is a demoralising kind of thing. So, again it's trying to inform people without hurting their pride or hurting their feelings (...), or making them feel so inadequate."

FATHER, 35, AFRICAN CARIBBEAN ORIGIN

Unmet expectations

Young men and women expected relationships of equality and involvement in services in tune with government policy. Fathers, however, felt this was rarely achieved in practice. Consequently, fathers felt marginalised during the process of ante-natal care. In keeping with a lack of engagement, some fathers shared experiences of stereotyping, racism, a lack of choice and in some cases, neglect.

"That's what it felt like but then I just, again, I made an assumption that, okay, a lot of fathers, especially in certain areas and from ethnic minorities, they're not really that supportive, so perhaps they had that perception. But I just thought it was unfair, 'cos I wasn't one of them, you know? But I, in fact, throughout the pregnancy, I felt like that. There were times when it would be, it would be like mother and person, who's the third guy in the room?"

FATHER, 27, AFRICAN ORIGIN

Fathers, young men and women felt they needed support, especially as they found ante-natal care confusing. They were not sure of what was expected of them or how they should make sense of the information provided. The research, however, identified several examples of good practice in which fathers felt supported and engaged. This was usually in the context of specialised professionals.

“But certainly a lot of the men do ask questions and we make sure that they know that they’re both in the process, not just the woman. It’s not a woman’s issue, it’s a couple’s issue, and therefore we give him as much chance to ask questions as we do her. I certainly always say to them, you know, ‘Do you have questions to ask me? Do you understand it?’ I ask him about his siblings, I ask him about his family, as well as I ask the woman. So, the focus is not always the woman, it’s about, the focus is on them as a couple, and I think, you know, certainly one is to get that balance, so that the guy doesn’t feel as if he’s just an addendum to his partner.”

HEALTH CARE PROFESSIONAL

Nonetheless, some health care professionals, although indicating a commitment to a ‘couple-centred’ approach, struggled to put this into practise because of operational barriers and resource constraints. Furthermore, while some mothers and fathers may no longer be together, fathers still wanted engagement even if the future relationship with the mother was uncertain. Fathers envisaged a relationship with their children and felt they had a ‘right’ to be included in decision-making. Practitioners found this difficult to negotiate.

Other fathers expressed the need for support in coming to terms with fatherhood, especially when the pregnancy might have been unexpected or there were difficulties. More generally, most fathers felt the social and emotional consequences of becoming a father were neglected by services because of the emphasis on testing. Additionally, they might be worried about other health issues, the mother’s health or other conditions affecting the baby; testing for sickle cell might not be high on the father’s agenda.

Organisational barriers to engagement and informed choices

Practitioners and commissioners identified re-organisation of the NHS, limited resources and a lack of understanding about future population needs as detrimental to facilitating choice. Lack of continuity was also seen to undermine timely interventions. Some practitioners, for example, noted that mothers often had contact with many different midwives when pregnant. Equally fathers felt a good relationship between mother, father and midwife was key to engagement and the exercise of choice. This is why fathers highly valued

continuity of care. In addition, fathers related how much they appreciated the specialist sickle cell nurses, genetic counselling and consultants with specialist knowledge. Fathers spoke of how these practitioners were able to support them, their wives and children during the process of making difficult decisions.

“Yes, the sickle cell nurse at the time was very good. Very supportive. She came around to visit quite often, supporting my wife. My wife was so emotional, you know, and there was always that worry, oh, you know, before the child was born mostly, how is it going to, how are we going to live?”

FATHER, 42, AFRICAN ORIGIN

All fathers related concerns about screening in primary care; from inability to get timely appointments; insensitive requests to also test for HIV in addition to sickle cell; and a lack of GP knowledge when offering choice and understanding the consequences of different carrier states.

Negotiating screening

The invitation to test the father of the baby for sickle cell has to be negotiated by service practitioners through the mother. The closeness of the couple relationship and influence of the (extended) family and how they view sickle cell could be important factors in how couples talk about ante-natal screening. Fathers felt practitioners did not always understand this. Some fathers had particular anxieties about the consequences of sickle cell, especially if they had previous experiences of the condition. Many fathers also alluded to a culture of silence, cultural myths and taboo linked to sickle cell.

“You know, back home, over there, they have an idea about people who does have sickle cell, that they cannot live over eighteen years old (...) I’ve seen people around me dying and then I don’t know exactly what was the death relating to. By coming over here, that opened a bit of my mind, especially through my wife, and having a kid who is a sickle cell.”

FATHER, 42, AFRICAN ORIGIN

Fathers also doubted some practitioners' commitment to couple-centred care. Fathers felt the focus was nearly always on the women and although they understood this, many felt practitioners were reluctant to challenge mothers' views. Fathers understood they had an important role in supporting their partner, but that service provision was poorly adapted to facilitate this.

"(...) because she were really affected by the news. I was trying to just be there for her. Just to help her take the shock (...) No disagreement, they were things she wanted because she didn't want to get rid of the baby, so I have to go for it."

FATHER, 37, AFRICAN ORIGIN

Some mothers were said by fathers to control decision making and not consult with the father. They were also said to refuse male involvement; limit the information they give men; blame men for non-involvement; use men as a reason for not taking certain tests or let men take the responsibility for all decision making. Such comments, whatever their merit and validity, demonstrate the potential complexity of communication during ante-natal care, particularly since fathers often felt they had little opportunity to discuss mothers' decisions with health care professions.

Overall, most mothers and fathers felt under pressure to ensure 'ideal' displays in ante-natal care in a way that demonstrated their competence as responsible parents or present a perfect front. This perhaps explains why some fathers felt judged, while a few felt they could not live up to what they thought was expected of them by both mothers and practitioners. Further, not all fathers were comfortable with the idea of fatherhood especially if there was a chance their unborn child had a disability. These fathers said they had little opportunity to discuss their anxieties, particularly since they were aware of the negative moral ascriptions associated with such views.

"Men feel that, you know, they mustn't be seen to be defective in any way and therefore, you know, when you test them and find that they're a carrier, you know, they feel that it means that they are weaker, and the whole concept of being weak is paramount to saying that they're not really a man and they're not manly because they've got this defect. (...) the cultural attitudes to sickle cell disease, particularly in Nigeria, is very pronounced in that, you know, people feel they'll be rejected if it is known that they've got a child with the disease or that they themselves carry, you know, this unusual haemoglobin."

HEALTH CARE PROFESSIONAL

The difficulties faced by service provision when offering good quality care and specialist support occurred irrespective of a father's ethnic origin. Nonetheless, fathers noted that information about screening and ante-natal care was largely medicalised and not especially culturally sensitive. Some practitioners, however, did demonstrate sensitivity to fathers' concerns.

The role of voluntary and community organisations in providing balanced information and support to carriers cannot be overstated. Voluntary and community organisations were especially useful in providing information about children and adults living successfully with sickle cell disorders. Such organisations were also trusted by fathers, especially among those who have had negative experiences of NHS provision.

"(...) they won't even go to their own GP, let alone for something like this. So, coming to our centre is a major thing. And if we're not there I think, to be honest, I don't believe that people will, they're not going to all start running to their GP because they haven't done it in the past and they're certainly not going to be going directly into the hospitals. We were filling that gap. I think our service was filling that gap, and it was even better if they could come to our centre or go to somewhere in the community where they felt comfortable, you know. That's the first port of call. People have to feel comfortable and comfortable in a place that they know. That they can trust. That the people are experienced and can understand where they're coming from."

VOLUNTARY SECTOR PROFESSIONAL

Divisive Ethical Issues

"That's their choice. But, you know, sometimes for us it's difficult because then our managers ask what we should do if they don't want to contact, and why you don't test them? What are you doing with those fathers who refuse testing? So, we encourage them by giving them information, but we can't force them. This is informed choice, is not forced choices. So, some fathers, they refuse straight away. "Yes, we know, and I don't want a test." And sometimes, as you say, they have other factors why they don't want to."

HEALTH CARE PROFESSIONAL

Health care professionals are aware of how screening can be ethically divisive. Some warn of a subtle pressure being exerted on them to test fathers to enable them to meet targets. Others explained they could cajole fathers and talk about 'asking' or 'having the father tested' rather than 'inviting fathers'.

"As I said, it's only been a couple of times that I've had that happen, cos I think sometimes you can shame, this sounds really bad, you can shame them into having the test (...)."

HEALTH CARE PROFESSIONAL

Both professionals and fathers related how information is not always shared among different practitioners or carried over to subsequent pregnancies. This undermined fathers' confidence in service provision. Fathers also expressed concerns about privacy and confidentiality and wanted to know more about what would happen to their test results.

Another area of concern for fathers was around prenatal diagnosis (PND). This is a test to find out if a baby has sickle cell. Fathers felt it was presented as an automatic response as soon as they were identified as an 'at risk' carrier couple. Fathers felt the risk of PND was sometimes downplayed and more generally, would have liked more support throughout the process. Fathers felt especially unsupported if results indicated that the unborn child had sickle cell and questioned the ethical provenance of phrases like 'testing for the baby's health' when the baby could be tested after birth.

"Yeah, if you ask me today to choose again for that injection I'm going to say no, because I can't see the difference. I mean later on, I was thinking that as soon as we, you know that the baby is sickle cell disease, you start the treatment."

FATHER, 38, AFRICAN ORIGIN

This is why fathers commented on the need for more sensitivity on the part of practitioners and especially midwives. Several fathers related feeling as if they and their wives were being pressurised by midwives towards termination at very late stages in pregnancy.

Most fathers agreed there was a need for more information, support and resources during ante-natal care and testing for sickle cell. Some fathers also related examples, where even after having affected children, they were not informed or given access to reproductive technologies in subsequent pregnancies. Fathers also remarked on needing to understand the care their child will receive if they did have a sickle cell disorder. Overall, fathers felt that once identified as 'at risk', there was little detailed discussion of the choices of treatment, research and care of those born with sickle cell disorders. They felt this was important information to have, when making a decision about what to do next.

Fathers expressed doubts about how much choice they really had during ante-natal screening and few thought they had made informed decisions. They felt, for example, it was their responsibility to ask the correct questions and actively seek information from other sources.

"We've kind of come to terms with knowing that it's not their responsibility, it's, to feed us with the information that we need, it's rather more our responsibility to ask to get that information out of them."

FATHER, 40, ASIAN ORIGIN

Additionally, those who felt they received poor care or experienced racism found it difficult to lodge a complaint.

Conclusion

Fathers expressed ambivalence about their encounter with ante-natal care. They were familiar with an emphasis on couple centred care, which they appreciated. Their experiences, however, often belied this emphasis. Consequently, many fathers felt marginalised by current provision, which might explain their lack of engagement with screening services. From a father's point of view, ante-natal care seems to conceptualise them as a 'risk' rather than a father with rights to care, who can refuse testing and request counselling; irrespective of what choice he makes.

Fathers commented on how supported they felt when they encountered health care professionals that engaged with them, gave them space to talk and encouraged them to ask questions. Health care professionals who respected them as prospective fathers demonstrated examples of good practice, which promoted good care and built trust. Fathers spoke especially highly of their contact with professionals such as specialist nurses, genetic counsellors or voluntary sector professionals. Unfortunately, such contact was the exception rather than the rule.

Health care services cannot engage with all the barriers our research identified, such as difficulties for working men to attend ante-natal appointments. However, services can become more inclusive by ensuring involvement. The policy commitment to ensuring men become an embodied part of ante-natal care, means there needs to be a genuine commitment to couple centred care. This is unlikely to be straightforward for both practical and philosophical reasons. However, it would be useful to have a considered debate on what the role of the father should be, in a way that does not compromise the care or rights of the mother. Further, young people, migrants and asylum seekers, indicated a lack of understanding about what services they had a right to access, where they could find those services and – more generally – the choices available to them. These fathers often said they experienced more problems such as racism, disempowerment, marginalisation or lack of choices. Our research also indicates a more general need for ethical training among practitioners, especially in relation to reflecting on their own values, when facilitating choice.

Sickle cell is a transnational issue and part of

a global public health agenda. Information on sickle cell, however, is largely given during ante-natal care, with a focus on medical and genetic consequences, rather than being socially embedded. Such information rarely reflects the complexities of people's lives. Fathers expressed concerns about the lack of possibilities and capabilities on the part of health care agencies to support choice; and when investing in better support for carriers and people with sickle cell disorders across the life-course. Ethically, screening provision should exist alongside investments in care and a commitment to encouraging a vibrant voluntary sector. This will help facilitate genuine choice among couples.

"I think all this attention on screening is because it's cheap. It's taking the easy way out. Screening just tells you more of the people that are ill, the people that have the disease, and you see why I don't like it in a way is, even though it's a choice, and that's something I've said to my wife, (...) probably that's reducing the, more people with sickle cell, so reduce the costs."

.....
FATHER, 38, AFRICAN ORIGIN

Recommendations

Our recommendations are based on current good practice that engages and empowers men, while being sensitive to the needs of the mothers. Such good practice is already being offered by some practitioners. Fathers would like to see good practice more widespread.

Recommendations for Mothers, Fathers and Families

- Sickle cell is the most common genetic disorder in the United Kingdom. Yet many health care professionals may not be aware of the condition. Ensure you get the access to the best services that you feel that you need.
- Sickle cell can affect anybody but is more common in people of African, African-Caribbean, Indian, Arab and Southern Mediterranean origin. In order to find out if you may be affected, try and gain an awareness of your family history and health.
- Young people need role models to understand how to talk about these issues that affect them. This includes their families, friends and health care professionals.

“...if you always grew up, grew up knowing what you were and everything, I don’t think it would be a problem bringing it up.”

YOUNG MAN, MIXED ETHNIC ORIGIN

- Information on sickle cell disorders and carrier status may not always be given in school or may focus purely on the medical or genetic consequences. Young people also need to gain an understanding of what it means to live with sickle cell.

“I personally really think that this should be discussed when they are at secondary school from the age of thirteen. When they start to be taught about sex education, I think that’s when they need to be taught about the issue around screening and obviously sickle cell and thalassaemia.”

HEALTH CARE PROFESSIONAL

- Testing for sickle cell can occur at any time and is your choice to make. You do not have to be in a relationship or thinking about children to have a test.
- If you are a carrier or have sickle cell, do become aware of your reproductive choices regardless of whom you fall in love with. It is important to be aware of all the options available to you.
- Generally, a woman will be invited to have a test for sickle cell during ante-natal care to find out if she is a carrier. If she is a carrier, her partner will be invited for a test during ante-natal care. These tests are not routine but offer choices with pros and cons.
- If you have been tested elsewhere or outside of the United Kingdom, you may be invited to repeat that test despite knowing your carrier status. Discuss this choice and why it is being offered to you.
- If you and your partner are both found to be carriers, there is a one in four chance that your child might be affected. You will be offered counselling. Discuss what questions you want to ask beforehand. Consider gaining follow-up information with a voluntary sector organisation.
- You can have a test during pregnancy to find out if your child has a sickle cell disorder. There

is a small risk associated with miscarriage. No one can tell you how severely affected a child will be. Treatments are, however, available. Your choice is to continue with the pregnancy or terminate it. This is not an easy decision to make and a decision that is right for one person might not be right for you. People, for example, agree to a test for different reasons; some use it to make a decision about termination, others to prepare themselves for the birth of a child who has the condition. It is your and your partner’s choice about what to do.

- Your child will also be tested after it is born. If it has a sickle cell disorder, the child will be given appropriate treatment. Discuss when and why you need to find out and if prenatal testing is an option for you.
- If you have a child with sickle cell, it is sometimes useful to get in touch with voluntary sector organisations, medical specialists and local services to ensure that you have all support you need.
- Sickle cell is a variable condition and affects everyone differently but can be very serious. There is at present no cure. Bone marrow transplants are sometimes used, but are not accessible for everyone. Transplants also carry serious health risks.
- Mothers, fathers and siblings need support but are often overlooked in services. This is a long standing problem. It is, therefore, important for families to understand what is available to them and support each other. Discuss if you want to be tested too and what that means for you as a family.

Recommendations for Health Care Professionals: Testing Men

“Just to be asked that would make me feel invited to, you know, be able to put my point across (...) you’re not just feeling (...) it doesn’t just feel like a process that you’re going in this end and you’re going to come out at the other end, that you’re actually aware of what’s happening every step of the way, and I think little things like that would make a massive difference.”

FATHER, 40, ASIAN ORIGIN

- Men related numerous barriers to access services. Make fathers feel welcome, valued and respected.
- Ensure services are accessible to working fathers and young fathers.
- The test is a polite invitation. Fathers, however, sometimes felt under pressure to have this test. Facilitate choice and discuss the options with families. Fathers appreciate this.
- Has dad received the *Tests for Dads* leaflet or an NHS letter inviting him to get tested? Does he have any questions? Does he know what sickle cell is?
- Fathers find ante-natal care confusing. Have you explained why you are doing the test? And discussed the pros and cons of testing?
- Have you explained that this test is just for sickle cell and nothing else?
- If a dad wants a HIV test or STI test refer him to GP or STI clinic.
- Show men exactly what you are going to do with their blood, explain how it will be kept and illustrate the labelling. Fathers said they were reassured by such explanations. Explain how long results will take.
- Draw attention to what happens if results show he is carrier. Ensure that he can always have someone to contact if he has questions.
- Father can sometimes be anxious about fatherhood. This is their priority rather than agreeing to have a test. Reassure them.
- Fathers understand why ante-natal care focuses on the mother. They would, however, like to see more couple centred approaches, in which they can express their needs.
- Understand that some men may refuse testing. This is their choice. They may test at another time or never at all. Ensure that fathers are aware they can make choices.
- You can probe to find out why a man refuses testing. Be non-judgemental and ask if he has concerns about needles or what a blood test may reveal.

“They feel that something else is gonna come up. So, if they smoke. Give you an example, if they do drugs, smoke weed or they do cocaine or whatever they do in their private life, they just think that the screening is gonna highlight all that, okay?”

HEALTH CARE PROFESSIONAL

- Ask if he has been tested before and where. Extra sensitivity is needed if a father is identified as being from a country that has a high incidence of faulty tests or where counselling is required before marriage.
- Ensure fathers have access to balanced information on the life of someone with a sickle cell disorder. For example, explain that new born screening enables early treatment and precautions to be put in place to best care for their child. In this respect, the voluntary sector can be an important source of information about the lives of families with a child with sickle cell.

Recommendations for GPs

- Ensure that sickle cell is brought up in general consultations if a genetic possibility and probe family histories if needed. Fathers and mothers sometimes feel it is too late to offer testing when pregnant. They would like to be offered a test sooner.
- Irrespective of apparent ethnicity consider offering a screening test for sickle cell/ thalassaemia as part of the package offered when first registering at a GP surgery.
- Respond positively to requests from any patients for a sickle cell screening test. Explain difference between sickle cell disorder and ‘carrier’ status.
- Testing should be an individual's choice but discuss pros and cons. Ensure you have leaflets and information available. At present, fathers do not feel they are making informed choices.
- If tests have taken place elsewhere, probe and suggest repeat tests if necessary.
- Be ready to explain carrier status, where to go for counselling and implications for pregnancy. Understand how some couples might find screening stigmatising.

- Provide information about reproductive possibilities if mother and father are both carriers or one partner has sickle cell.
- Ensure you are up to date with what your local voluntary sector organisation offers and know where to refer your patients.

Recommendations for Genetic Counsellors

- Having time with a specialist is highly valued by all parents but they feel that they cannot always articulate their questions. Make sure that they feel supported to ask 'stupid questions' and ensure access to interpreters if required. Make sure mothers and fathers get to ask all their questions.
- Ensure equity in services and access to all reproductive choices for everyone. This means giving choices to couples with carrier status and both men and women who have sickle cell.
- When dealing with young men explain how to instigate conversations with peers about sickle cell testing. Highlight role models and positive links to sickle cell to combat possible stigma.
- Be sensitive to the lack of awareness and information about sickle cell in British society. It is still perceived as a 'black disease', so show understanding to how this may affect men's conceptions of identity and understanding of testing.
- Be sensitive to the differing socio-cultural background of mothers and fathers and role of extended family.
- Timing is crucial for parents. Test results have to be given early to enable men and women to make informed choices that they find difficult.
- Check information given about carrier status and why a card is given. Explain specific situations a person may encounter such as; operations, high altitudes and why donating blood is possible.
- Make sure that you explain that prenatal diagnostic testing is neither a cure nor a treatment for sickle cell and has a risk of miscarriage. Explain why you are giving this choice but also that the child can be tested after birth.
- Some fathers may only find out they might be carriers after a child is born. Ensure access to counselling services for these fathers.

- Ensure reproductive choices are given for the next pregnancy.

Recommendations for Clinical Commissioning Groups and Specialist Commissioning

- Be aware that sickle cell is a leading genetic condition in England. Obtain up-to date figures from NHS England. For example at the time of writing 1 in 450 'White-British' new-borns carries a sickle cell-relevant gene, 1 in 1850 of all births in the UK is a child with sickle cell disorder and 1 in 70 is a sickle cell or thalassaemia carrier.
- Health care professionals, such as midwives and genetic counsellors, feel their resources and time are being stretched and that the focus is more on delivering targets than ensuring proper and appropriate care. They would like more support to ensure good care for mothers and recognition of the difficulties they face in providing this. If fathers are encouraged to engage with ante-natal care, especially if genetic testing of men becomes part of ante-natal or primary care, planning for the future needs of this group is essential. Practitioners would also like more advice and support on how best to engage with fathers.
- Consider making resources available to support GPs who offer sickle cell screening in primary care, or consider commissioning voluntary groups to undertake this provision.
- More education and awareness about sickle cell is needed. This does not necessarily mean providing clinical information or ensuring that genetic education is provided in schools. Parents require information linking the social consequences of decision making with clinical material. Information also needs to be more readily accessible (such as translated accounts, using social media and 'apps' and more community resources) and in some cases specifically geared towards men.
- Involve the local voluntary and community services to ensure that outreach includes fathers. Voluntary sector providers have an excellent track record of engaging with local communities and are often more trusted than NHS provision.
- Ensure that patients, carriers and voluntary organisations for sickle cell are involved in

Clinical Commissioning Groups as well as Specialist Commissioning. Consider setting up a taskforce to ensure this and make sure community members with a good knowledge of sickle cell are included.

- Ensure that services are inclusive of fathers and that they are welcomed across the board (from ante-natal care to more specialist provision). This would also achieve equity and reduce inequalities.
- Ensure the provision of specialist services, as well as counselling, for fathers and families affected by carrier status.

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“More awareness and more involvement for dads because again, I’m, it’s something in the back of mind that I’ve got and just to let dads know that, okay, if you are a carrier, it’s not the end of the world type of thing.”

.....
FATHER, 35, AFRICAN CARIBBEAN ORIGIN

The research team for this project included: Karl Atkin and Maria Berghs, University of York; Simon Dyson, De Montfort University; John James, Sickle Cell Society, and was supported by the Leeds Teaching Hospitals NHS Trust. For further information please contact Karl Atkin (karl.atkin@york.ac.uk).

Useful Contacts

Most major cities now have a Centre for Sickle Cell and Thalassaemia. To find yours: www.sickle-thal.nwlh.nhs.uk/Information/NationalSickleCellThalassaemiaCentres.aspx

The voluntary sector contacts of the organisations that participated in this report:

Sickle Cell Society

54 Station Road
London
NW10 4UA
Tel: 020 8961 7795
Email: info@sicklecellsociety.org
Web: www.sicklecellsociety.org

OSCAR Sandwell

120 Lodge Road
West Bromwich
West Midlands
B70 8PL
Tel: 0121 525 0556
Email: oscar-sandwell@hotmail.co.uk
Web: www.oscarsandwell.org.uk

Sheffield Sickle Cell and Thalassaemia Foundation: – SSCAT Foundation

SYAC Centre
110-120 Wicker
Sheffield
S3 8JD
Tel: 0114 275 3209
Email: sscatf1@btconnect.com

OSCAR Nottingham

31 Hungerhill Road
Nottingham
NG3 4NB
Tel: 0115 960 7755
E-mail: oscarnottingham@live.com
Web: www.oscarnottingham.org

OSCAR Birmingham

22 Regents Place
The Jewellery Quarter
Birmingham
B1 3NJ
Tel: 0121 212 9209
Email: admin@oscarbirmingham.org.uk
Web: www.oscarbirmingham.org.uk

Liverpool Sickle Cell and Thalassaemia Support Group

Based at: Abercromby Health Centre
Grove Street
Liverpool
L8 6JJ
Email: liverpoolsicklecell@gmail.com

Leeds Sickle Cell Support Group

Based at: The Reginald Centre
263 Chapeltown Road
Leeds LS7 3EX
Tel: 0113 843 4348
Email: sue.jammeh@nhs.net

ASYABI – Sickle Cell Yorkshire

Email: sicklecellyorkshireasyabi@yahoo.fr
Web: www.asyabi.co.uk

Sickle Cell Care –Manchester

Email: Admin@sicklecellcaremanchester.co.uk
Web: www.sicklecellcaremanchester.co.uk

Useful Resources

NHS Sickle Cell and Thalassaemia Screening Programme (now part of **Public Health England**) contains information and leaflets about screening, sickle cell and carrier (trait) statuses. This is also in different languages: <http://sct.screening.nhs.uk/>

You can watch videos of people discussing their experiences of sickle cell, couples' decisions during screening and what carrier (trait) status means: <http://sct.screening.nhs.uk/stories>

They also have a link to **Healthtalkonline** which is a website about people's experiences and is in languages such as French, Urdu and Portuguese: <http://healthtalkonline.org/peoples-experiences/pregnancy-children/screening-sickle-cell-and-beta-thalassaemia/topics>

NHS Newborn Blood Screening Programme (now part of **Public Health England**) explains the blood spot test used in babies to identify sickle cell and carrier (trait) status: <http://newbornbloodspot.screening.nhs.uk/>

NHS CHOICES has information and videos of people and children talking about what it's like to live with sickle cell: www.nhs.uk/video/pages/sickle-cell-anaemia.aspx

Planet Sickle Cell is a special website for children living with sickle cell: www.sicklecellsociety.org/websites/123reg/LinuxPackage22/si/ck/le/sicklecellsociety.org/public_html/pages/children